DOCUMENT RESUME

ED 439 872 RC 022 344

AUTHOR Hider, Erin D.
TITLE A Qualitative Study of the Child, Family and Professional Factors That Influence the Use of Assistive Technology in Early Intervention.
PUB DATE 2000-03-00
NOTE 7p.; In: Capitalizing on Leadership in Rural Special Education: Making a Difference for Children and Families. Conference Proceedings (Alexandria, VA, March 16-18, 2000); see RC 022 337.
PUB TYPE Reports - Evaluative (142) -- Speeches/Meeting Papers (150)
EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Assistive Devices (for Disabled); Case Studies; Disabilities; *Early Intervention; *Family Programs; Preschool Education; *Resident Camp Programs; *Young Children
IDENTIFIERS *Technology Utilization

ABSTRACT

Factors involved in assistive technology use by young children with disabilities were explored through case studies of five families who had received intensive training at Camp Gizmo, an assistive technology camp for young children. Families, service providers, and preservice students in special education and speech language pathology engaged in a weeklong intensive training in assistive technology while the children participated in camp activities. The five children were aged 2-4. Each family was assigned a team of other families, early interventionists, teachers, and college students who observed the children as they tried out assistive devices. Each family documented the observations, kept family diaries, developed goals and action plans to use after camp, and participated in interviews before and after camp and 6-8 months later. Case studies include family background; assistive technology use before, during, and after camp; opportunities and barriers to assistive technology use; and effects of assistive technology use on the family. Findings indicate that Camp Gizmo had little impact on assistive technology use. All families increased use of assistive technology, but other factors contributed to the increase. Delivery system factors were the most important barriers to assistive technology use. Recommendations are offered regarding Camp Gizmo, professional training, and removing system barriers. (SV)

Reproductions supplied by EDRS are the best that can be made
from the original document.

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Judy Weyrauch
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

ED 439 872

Erin D. Hider, Ed.D.
Clarion University
Clarion, PA

A QUALITATIVE STUDY OF THE CHILD, FAMILY AND PROFESSIONAL FACTORS THAT INFLUENCE THE USE OF ASSISTIVE TECHNOLOGY IN EARLY INTERVENTION

The purpose of this study was to explore the individual, system and environmental factors involved in assistive technology use by young children with disabilities through case studies of families who had received intensive training at Camp Gizmo, an assistive technology camp for young children with disabilities, which was co-sponsored by several state agencies. Families, service providers, and preservice students in special education and speech language pathology engaged in a weeklong intensive training in assistive technology while their children participated in camp activities.

Procedures and Methodology

A case study was done with five families who attended camp in July 1997. Four of the children participated in local Early Intervention programs and one attended a preschool class. The group contained four children aged two to three years old and one child aged four years old. Four children had severe physical and mental disabilities and one had Down syndrome.

Each family was assigned a team at camp that consisted of other families, early interventionists, therapists, teachers, and college students. To determine the children's assistive technology needs, the teams observed the children as they tried out various assistive devices. Every family and team at camp documented the observations, kept family diaries, student diaries and developed goals and action plans to use after camp.

Each family participated in a series of interviews: one before camp, one immediately after camp, and a final interview six to eight months later. Each interview consisted of a set of open-ended questions and some probing questions, which focused on camp, assistive technology use before and after camp and the effect of assistive technology use on family life. Each family was observed in the home and at therapy sessions on at least three visits over a period of six months after camp. The children were also observed in their early intervention programs, preschool and daycare.

Data Analysis. In this qualitative case study, data were analyzed according to procedures described by Miles and Huberman (1994). These procedures consisted of coding the information, identifying themes and trends in the data and developing an explanatory framework.

Construct validity was assured through use of multiple sources of evidence (Yin, 1994) from interviews, observations, and review of documentation. Camp Gizmo staff members and parents reviewed the case study reports to verify the information (Mertens & McLaughlin, 1995). Internal validity was strengthened by having someone who was not knowledgeable about the project review the analysis and findings (Mertens & McLaughlin, 1995).

The Smith Family

Family Background. The Smith family consisted of Andy, three years old, and his mother and father, Inez and Tom. Tom worked full time; Inez was the primary caretaker. The Smiths lived in a mobile home in a small town. Andy's cerebral palsy affected his motor skills to a high degree. He was just beginning to say words and was believed to have average intelligence.

R022344

BEST COPY AVAILABLE

Assistive Technology Use Before, During, and After Camp Gizmo. Inez was an avid user of technology. She was disappointed that the camp did not have more equipment to demonstrate because not much was available for Andy to try that he had not tried previously. Andy's assistive technology use increased after camp. He began using an AlphaTalker™, an augmentative communication device, at therapy, but not at home. His mother obtained a computer for him to use through the Family Support Program. He learned to drink out of an adapted cup. He used a gait trainer and a stander at home before and after camp. He was evaluated for a power wheelchair. He continued to wear an ankle foot orthotic.

Opportunities and Barriers to Assistive Technology Use. Andy loved to use technology. Inez was a parent who pushed use of assistive technology, but since Andy loved to use it they worked well together. The environments in which Andy worked and played were technology rich, which gave him ample opportunity to practice skills in a variety of places and situations. Inez was lucky to have an insurance company willing to let her try whatever technology she thought would assist Andy. Some professionals in her life were supportive of assistive technology use: the early interventionist and speech and physical therapists. Although even one of the supportive people, Andy's physical therapist, was only supportive of a portion of what Inez was doing. Other professionals were not supportive of her needs, especially some of the physicians that she encountered.

Effect Of Assistive Technology Use on the Family. The responsibility to take Andy to his therapy sessions fell on Inez since she was his primary caretaker. She was responsible for implementing use of the assistive technology equipment at home. She put him in the stander, gait trainer and on the seating bench each day. When asked about the effect of assistive technology on her family life, Inez said they had a normal family life. She admitted that she was so used to the hectic schedule that it was normal to her. She did become frustrated when she had to fight the equipment to get Andy in it or when she had to move furniture in their mobile home around for the equipment.

The Everest Family

Family Background. The Everest family consisted of Hannah, five years old, her mother and father, Ima and Mark, and two older sisters. They lived in a medium-sized single family dwelling in a city. Mark worked full time as a lawyer; Ima was the full time caretaker of their daughter. Hannah had hypomyelination and translocation of chromosomes 4 and 12 - no known syndrome. She was delayed in all areas of development. She did not speak and had low muscle tone. Hannah attended preschool from 11:30 a.m. to 2:30 p.m. Tuesday through Friday at a school that was not her local school.

Assistive Technology Use Before, During, and After Camp Gizmo. Hannah's action plan primarily consisted of using a simple communication device at home and school. After camp, school staff started using the BIGmack™ with Hannah during circle time and other activities. Ima struggled to get Hannah to use the device at home. She had success after consultation with a private speech therapist, who was working with Hannah on oral stimulation. Ima continued to work with Hannah on the computer with switch access that she had used before camp, but Ima had difficulty keeping Hannah interested. Hannah was fitted with new wheelchair after camp, which improved her seating.

Opportunities and Barriers to Assistive Technology Use. Hannah was inconsistent in her response to assistive technology and rejected many of the toys or devices presented to her. Ima was frustrated by Hannah's lack of progress, but managed to keep focused on her goal of increasing Hannah's independent functioning. Ima was given hope by the private speech therapist, who worked with Hannah on the BIGmack™ as well as on feeding issues. Hannah's environment was rich in technology both at home and school. The technology that Hannah used was well suited to meet her goals. Hannah's new wheelchair helped her sit much straighter. The degree of support from the professionals working with the family varied widely. For instance, her occupational therapist started but did not finish an occupational therapy evaluation that was needed for Hannah's IEP.

Effect of Assistive Technology Use on Family. Ima's schedule with Hannah was busy; she took her to preschool and therapy every day. Ima spent a great deal of time trying to get Hannah to eat. Assistive technology use was secondary to the feeding issue, because a physician at the feeding clinic scared Ima by telling her Hannah could die during feeding.

The Newton Family

Family Background. The Newton family consisted of Matthew, three years old, and his father, Doug. Doug worked full time at a research facility. They lived in a comfortable one-family home in a suburban housing tract. During the day while Doug was at work, Matthew was cared for by one-to-one trainers in the morning, attended school in the afternoon, and went to daycare the rest of the day. Matthew had physical and cognitive delays due to agenesis of the corpus collosum. Matthew also had a cognitive visual impairment that prevented him from processing visual information. Matthew had problems related to feeding; he had reflux and difficulty keeping his food down. Matthew did not communicate verbally.

Assistive Technology Use Before, During and After Camp Gizmo. Before camp, Matthew communicated through crying, groaning and smiling, and other than switch toys, used no technology. After Camp Gizmo, Doug began working with a Say It Play It!™ rocker switch. The rocker switch had two messages that could be accessed by hitting one or the other side of the device. At the final interview, Doug reported, "We've worked with it quite a bit and actually I'm convinced that he does do it." Matthew had a Giraffe Stander™ that Doug obtained through his insurance plan after camp. Doug put him in it for fifteen minutes each day. Finding seating that Matthew could tolerate was a problem. Doug was negotiating with his insurance company to purchase a Snug Seat™ for Matthew.

Opportunities and Barriers to Assistive Technology Use. Matthew was unresponsive to most technology, but Doug was persistent and Matthew eventually did use the Say It Play It!™ rocker switch consistently. Matthew's environment was rich in technology and people willing to use it. Funding for devices was difficult to obtain and Doug had to fight with his insurance company to get the equipment Matthew needed. Matthew had a speech therapist, who was not supportive of assistive technology use. The physical therapist and the occupational therapist were supportive of assistive technology use but came at it from different directions and did not consult with each other.

Effect of Assistive Technology Use on Family. Doug did not think that using assistive technology really had much of an impact on his or Matthew's routines. He felt they incorporated its use into their regular routines.

The Steele Family

Family Background. The Steele family consisted of Anthony, two years old, and his mother and father, who lived in an older but large mobile home in a rural community. His mother, Erica, was Anthony's primary caretaker. After Camp Gizmo, she became pregnant with her second child. Erica's family lived nearby and provided support by helping Erica with transportation to and from therapy sessions and attending the sessions with her. Her grandmother also came to Camp Gizmo for the week. Erica discussed Anthony's disability. "It's still undiagnosed. Anthony has had a lot of health problems related to his disability. He had open-heart surgery two days after he was born to repair the aorta valve. He also had problems related to extra digits on his hands and feet."

Assistive Technology Use Before, During and After Camp Gizmo. Anthony's use of assistive technology decreased after camp. He tried a wheelchair and dynamic stander at camp. His mother borrowed a stander but Anthony would not use it at home. It took seven months for the family to get the wheelchair he was fitted for at camp. By then he had started walking a little bit using a walker, so they did not use the wheelchair much.

Opportunities and Barriers to Assistive Technology Use. Anthony made progress during the year despite poor health and physical problems. Erica worked with him daily on his wedge and bench when he was younger but did not keep it up when he got new equipment. The environment had some of the technology Anthony needed, but they did not have adaptive feeding equipment and the walker he had was not suited for use outdoors. The family did not have insurance and obtained equipment through the West Virginia Children with Special Health Care Needs Program. The professionals who worked with the family were not supportive of assistive technology use. A physical therapist assisted Erica by getting a wheelchair assessment but when the physical therapist left, her replacement did not follow-up on the wheelchair.

Effect of Assistive Technology Use on the Family. Erica had been very supportive and used the equipment with him at home after camp. She indicated at the final interview that she was using the equipment less because of conflicting advice from professionals. For instance, she did not use the stander because the speech pathologist recommended Erica put Anthony down on the floor and let him crawl while the physical therapist said he should walk as much as possible.

The Lemon Family

Family Background. The Lemon family consisted of Ian, two years old, and his mother and father, Helen and Brandon. Brandon worked full time; Helen took care of Ian full-time. They lived on a farm in a small community. Ian had Down syndrome and was delayed in both cognitive and language development. He did not speak but made and imitated sounds. He used ten to fifteen signs regularly. He had some delay in gross and fine motor skills.

Assistive Technology Use Before, During and After Camp Gizmo Except for adapted feeding utensils, Ian used no assistive technology before camp. The issue of augmentative communication came up with Ian at camp because he did not speak. The team tried some devices with Ian and reported that he showed no interest. The team suggested using a Picture Communication Exchange System (PECS) with Ian. Brandon and Helen thought it was a good idea but when they talked to the speech therapist at home, she discouraged them. The Lemons did not pursue it any further. The Lemon family came to Camp Gizmo because they were interested in the computer equipment. They put in their action plan that they would borrow a TouchWindow™ from the Early Childhood Library to use with their computer. When they returned home they were reluctant to borrow the TouchWindow™. Brandon and Helen eventually bought a Barney doll with software to use on the computer. Helen and Brandon chose self-feeding as a goal during camp. They tried some adapted spoons at home but reported that Ian did as well with a regular spoon as with the adapted spoon. He used a regular cup without assistance. Brandon said Ian would scoop with a spoon at school, but at home, Brandon put the food on the spoon and then handed it to him.

Opportunities and Barriers to Assistive Technology Use. Ian was not interested in any of the communication devices presented to him at camp. He was responsive to the computer equipment and used the TouchWindow™ appropriately. Brandon and Helen bought a computer and software to use with Ian, but were not comfortable borrowing the adaptive computer equipment they saw at camp. Adapted feeding utensils were available for Ian to use at his Early Intervention center but not at home. The speech therapist who worked with Ian discouraged the use of the PECS.

Effect of Assistive Technology Use on the Family. Assistive technology did not have much effect on Lemon family routines, since they did not use assistive technology. Helen had a book of pictures and the signs for each picture that she went through with Ian once a day. Brandon also spent time each evening working with Ian on the computer. They used a computer without any adaptations for Ian.

Recommendations

Provide Better Inservice and Preservice Training For Professionals Working With Families of Young Children. Camp Gizmo was one method to address the need for inservice training, but by itself, the camp did not meet the need. Professionals lacked training specific to the children and their home environments. Regional workshops to address the needs of children in their home and school environments were needed after camp. It might also be necessary to find other ways to get information to families and professionals since people in this study found it difficult to take off time from work to attend the camp. Derer, Polsgrove and Rieth (1996) presented a list of recommendations to increase dissemination of information to teachers: a toll-free hotline, an assistive technology newsletter, product reviews, district level specialists, networking at district level, and school level access to computer bulletin boards.

Preservice training is needed in assistive technology. Camp Gizmo was the only course devoted specifically to assistive technology in West Virginia, although the subject is incorporated into other courses. In a survey of teachers by Izen and Brown (1991), the teachers indicated they were not well prepared by their university training program in the area of assistive technology. In a more recent study, over one-half of special education teachers surveyed indicated that they had not been well trained in the area of assistive technology (Heller, Frederick, Dykes, Best and Cohen, 1999).

Provide a Comprehensive, Family Focused, Team Assessment. Camp Gizmo was never intended to be an avenue for assistive technology evaluations, but families desperate to find assistive technology solutions for their children treated it as such. Camp Gizmo could not be a substitute for a comprehensive evaluation, which should be conducted by a transdisciplinary team that includes, professionals, the child, and parents, and occurs in the environment in which the child is going to use the technology.

Provide Follow-up to Assessments. Camp staff needed to follow up with phone calls or visits to see if parents were able to arrange for evaluations by their home transdisiciplinary teams and to get the recommended assistive technology.

Increase Availability of Technology for Parents to Try and Use. Local and regional libraries of assistive technology should be maintained to give parents a local source of equipment to borrow and try out.

Provide Technical Assistance to Families and Professionals Parents and professionals need access to persons with special expertise when trying to set up equipment they have obtained for their children to use. In their study, Hutinger, Johanson and Stoneburner (1996) found a need for technical assistance and troubleshooting. They suggested that early intervention programs hire a technology specialist familiar with the needs of children with disabilities, who would need to get in-depth training on how to integrate the technology into the lives of children. Many assistive technology manuals are written in language that is not understandable to the average person, so providing simplified manuals in necessary.

Improve Transition of Assistive Technology. The families who were transitioning from Early Intervention programs to preschool expressed apprehension over the process. They were concerned that the preschool would not provide the expertise or individual attention their children had received in the past and that the same assistive technology would not be available.

Streamline Funding System to Make It Easier for Parents to Obtain the Technology Their Children Need. Four of the families in this study had difficulty in dealing with funding agencies. There are multiple funding sources for assistive technology, with multiple policies, eligibility criteria and priorities that guide what agencies will and will not fund. Funding agencies need to be made more accountable. Two of the parents in this study reported that assistive technology was delayed due to lost paperwork.

Inform Parents of Their Rights Parents need to be better informed of their legal rights and to have someone to help advocate for them if their rights are violated.

Limitations of Study

Families attended Camp Gizmo because they had an interest in using assistive technology. Besides being highly motivated to use technology, this group was also select in that four of the five families were middle class families who had access to private insurance. These families were able to take a week off from their family life or jobs to come to Camp Gizmo. Thus this group may not be considered representative of the majority of families whose children use assistive technology. The study only included five families, which may not have provided enough interviews or observations.

Summary

Camp Gizmo had little impact on assistive technology use for the five families studied. All the families increased use of assistive technology but other factors also contributed to that use. Those factors were identified by examining the overall opportunities and barriers experienced by the families as they attempted to use assistive technology with their children. Each family had unique experiences, but there were certain opportunities and barriers that cut across the families. The main barriers were in the areas of child, family, environment, technology, and system. The system barriers contributed most to the families not using technology after they left camp. System barriers must be addressed if children are going to have the opportunity to use technology effectively in their everyday lives.

References

Derer, K., Polsgrove, L. & Rieth, H. (1996). A survey of assistive technology applications in schools and recommendations for practice. Journal of Special Education Technology, 13, 62-80.

Heller, K. W., Frederick, L. D., Dykes, M. K., Best, S. & Cohen, E. T. (1999). A national perspective of competencies for teachers of individuals with physical and health disabilities. Exceptional Children, 65, 219-234.

Hutinger, P., Johanson, J., & Stoneburner, R. (1996). Assistive technology applications in educational programs: A case study report on state of the practice. Journal of Special Education Technology, 13(1), 16-35.

Mertens, D. M., & McLaughlin, J. A. (1995). Research methods in special education. Thousand Oaks: Sage Publishing.

Miles, M. B., & Huberman, A. M. (1994). Qualitative data analysis: An expanded sourcebook (2nd ed.). Thousand Oaks: Sage Publications.

Yin, R. K. (1994). Case study research. (second ed.). (Vol. 5). Thousand Oaks: Sage.